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ABSTRACT

Intended for the young adult with cystic fibrosis, the booklet provides information on dealing with problems and on advances in treatment and detection related to the disease. Addressed are the following topics: description of cystic fibrosis; inheritance of cystic fibrosis; early diagnosis; friends, careers, and other matters; treatment; mechanical aids; exercise; diet-pancreatic supplements; smoking; living arrangements; checkups; organizations; and prognosis. (SBH)

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living with cystic fibrosis

a guide for the young adult

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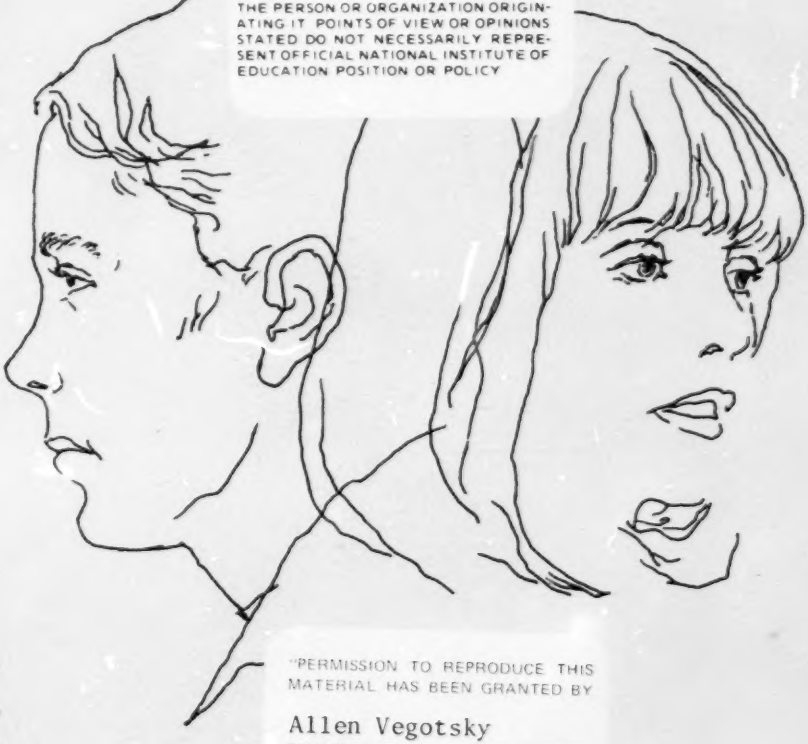

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CYSTIC FIBROSIS FOUNDATION

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FOREWORD TO THE REVISED EDITION

Growing up to take one's place in the adult world is a difficult business at best. For the young person with cystic fibrosis or other chronic pulmonary disorder, the problems are compounded by special considerations: If I go away to college, where can I obtain treatment? To what extent are my career choices limited? Should I look forward to getting married?

These and other questions are assuming increased importance as advances in the detection and treatment of cystic fibrosis improve the life prospects for many patients. To provide or suggest answers to such questions is a primary purpose of the present booklet. Another purpose is to offer up-to-date information about CF so that you will be better equipped to meet your new-found responsibility for maintaining your own health. Because of variations in the severity of this condition, there can be no ready-made set of rules for all; but with a basic understanding of the illness on your part and the cooperation of a physician who knows your special needs, you will find it possible to map out an effective individual treatment program.

The first edition of "Living with Cystic Fibrosis" was prepared under the supervision of the Professional Education Committee of the Cystic Fibrosis Foundation, consisting at that time of Dr. Harry Shwachman, chairman; Dr. Carl F. Doershuk, Dr. Richard R. Dooley, Dr. Bettina C. Hilman and Dr. Lucas L. Kulczycki. Dr. Hilman undertook the major effort of organizing and presenting the material which her fellow committee members and other physicians associated with the Foundation reviewed, criticized and helped refine through numerous drafts. The Rehabilitation Services Administration of the Department of Health, Education and Welfare also contributed valuable suggestions.

Since the booklet's initial publication, the Cystic Fibrosis Foundation, with government support and the cooperation of Cystic Fibrosis Centers across the country, has conducted a study of the problems of older individuals with CF as they seek opportunity and fulfillment in their daily lives. The survey findings are proving useful to the Foundation in planning programs intended to contribute to the broadening of such opportunity and the achievement of job satisfaction and economic self-sufficiency.

Although there has been some slight reorganization of the text and a minor change or two in emphasis, the message in the following pages remains unaltered. More can, and must, be done to help each young adult with cystic fibrosis realize his or her potential.

CYSTIC FIBROSIS FOUNDATION

THE NEW GENERATION

Sara Lou Prentiss, 22, is in graduate school in the Midwest working toward her M.A. in clinical psychology. She is engaged to a law student attending the same university.

Arnold Hendrickson, 33, has a Bachelor of Science degree in pharmacy and owns his own drug store. He stands 6 feet 2, works a 60-hour week, is married and has two adopted children.

Elaine Moore, 25, is devoting herself to nursing as a member of a religious order which she entered as a postulant when she was nineteen.

Tim Carpenter, 19, went from high school to Wall Street, where he is employed as a clerk in an investment house.

Peter Kaufman, in his late twenties, was an honor student in high school despite poor attendance because of illness. He went on to college to earn a degree in accounting. Today he holds a full-time job as a bookkeeper and is an ardent camper and skier.

Harold Sampson, 38, is a high school teacher, married, with one adopted child. A law school graduate, he decided after a number of years in practice to switch to the field he preferred. Another of Sampson's ambitions was realized during a recent summer vacation when he took his family on a tour of Europe.

You and these young, and not-so-young, men and women have at least one thing in common: cystic fibrosis. (The names used here are not real names, but the people themselves are real.)

Probably you have other things in common, too—some of the same problems, and the same kind of determination to work them through.

To deal effectively with the problems related specifically to CF, it is of course necessary to have a complete understanding of the condition. In terms of personal experience, there is no question that you have such an understanding; but you may never have had CF explained to you in any unified way. To fill in possible gaps in information is the purpose of the next few pages.

WHAT IS CYSTIC FIBROSIS?

The fact is that scientists are still trying to come up with an answer to account for this complicated and puzzling disease. We know more about it now than we did a few years ago, and in an era when the atom and the moon are both yielding up their secrets, it seems probable that we shall extend our knowledge of CF still further. Yet, for the present, we are better able to talk about the "how" of cystic fibrosis than the "why." We can describe it—even give the odds for its occurrence in the

population as a whole and certain families in particular—but we cannot say what causes it.

In brief, cystic fibrosis is a generalized disorder affecting most or all of the exocrine glands. These are glands that secrete to their outer surfaces, not inward to the bloodstream or lymph, as the endocrine glands do. Mucus, saliva and sweat are produced by the exocrine glands; in the cystic fibrosis patient these substances are chemically or physically abnormal.

The underlying cause of the abnormal sweat, mucus and saliva is not known. The sweat of patients with cystic fibrosis has an exceptionally high salt content; it is this finding that is the basis of the major and most reliable diagnostic test for the condition, the sweat test.

Most of the symptoms and complications of CF are associated with the unusually thick and sticky mucus which interferes with the functioning of the lungs and digestive system. Plugging of the ducts of the pancreas by mucus prevents enzymes needed for digestion, especially digestion of fats, from reaching the small intestine. When the disease was discovered in the 1930s, the pancreatic involvement was thought to be its main feature; small cysts noted in the pancreas led to the name cystic fibrosis of the pancreas.

Now it is known that the lungs are more often seriously affected than the digestive system. The poor absorption of food can be improved in most cases by taking pancreatic supplements, so it is the lungs that are likely to present the chief problem. For this reason the lungs receive particular emphasis in this booklet.

It should be kept in mind, however, that different patients may be affected differently by their out-of-kilter chemistry. For example, from 8 to 10 percent of babies with CF are born with an intestinal obstruction known as meconium ileus. This occurs when a tarry material plugs the small bowel. Surgery to relieve this block is usually required within the first few days of life.

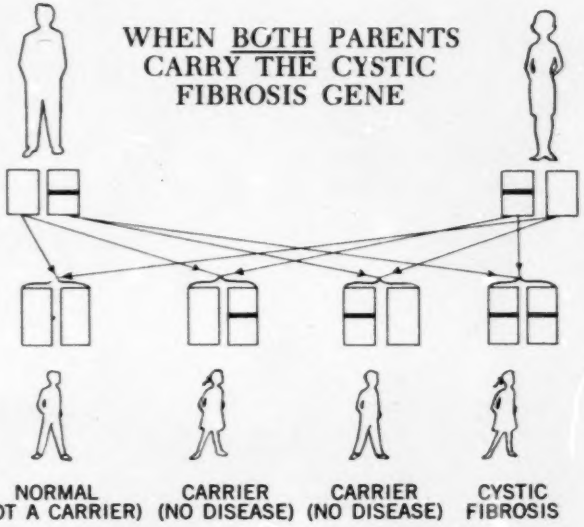
The mucus which causes trouble in the lungs is a product of cells lining the breathing tubes or bronchi. Normal mucus is thin and slippery and plays an important part in the cleansing process by which we expel germs and dust from our lungs and breathing passages. Instead of helping in this way, the tenacious mucus of CF tends to obstruct the smaller breathing tubes. Blockage by mucus of these small airways leads to infection which can damage the airway walls and lung tissue. Various methods to help thin the mucus and drain it from the bronchi can prevent obstruction and minimize much of the infection which produces this damage. Such methods include the use of mist tents, expectorants, aerosol inhalations and bronchial (also called postural) drainage.

INHERITANCE OF CYSTIC FIBROSIS

Cystic fibrosis is passed on in families by genes, the units of heredity in the cells. This condition is transmitted as a recessive trait, which means that the person born with it has received one gene for the trait from each parent.

It is possible for a baby to inherit a gene for CF from one parent and a corresponding normal gene from the other. The child then is free of the disorder but a carrier of the gene for CF, which may be passed on to the next generation. Or the baby may inherit only the normal genes from both parents and neither have CF nor carry the CF gene.

The diagram shows how these gene combinations occur.


WHEN BOTH PARENTS CARRY THE CYSTIC FIBROSIS GENE
NORMAL (NOT A CARRIER)
CARRIER (NO DISEASE)
CARRIER (NO DISEASE)
CYSTIC FIBROSIS

When the CF gene is present in both parents, there is a 50 percent (two-in-four) chance each time they have a child that the baby will be free of CF but will be a carrier. There is a 25 percent (one-in-four) chance that the child will have CF. There is an equal chance (again one out of four) that the child will inherit only the normal genes from both parents and will neither have the disease nor be a carrier.

These odds could be expected to work out with mathematical precision if large numbers of carrier parents and their offspring were considered collectively. The individual family unit, however, is too small to

permit accurate prediction. One cannot say that one child in four born to carrier parents will always have CF, that two will be carriers and one will be healthy and a non-carrier. There are some families in which three out of three children have CF, and others with only a single affected child out of nine or ten.

Cystic fibrosis is not rare as once believed; it occurs in approximately one in every 1,600 live births. As many as 5 percent of the general population may carry the gene—a fact of which few people are aware.

Studies now under way in Centers affiliated with the Cystic Fibrosis Foundation, and in cooperating institutions, offer hope for a test to identify the carriers of the gene for CF. At present, the only way people find out they are carriers is by having children with the disorder.

HOW IMPORTANT IS EARLY DIAGNOSIS?

With the development of the sweat test, it became a relatively simple matter in most instances to determine whether or not a patient has cystic fibrosis. In no other disease with which CF could be confused is there so much salt in the sweat. It has taken some years, however, for the great majority of doctors to think of cystic fibrosis when examining children with symptoms that resemble those of chronic bronchitis, asthma, whooping cough or other more familiar ailments.

The earlier a condition is diagnosed, of course, the sooner appropriate treatment can be started; yet it does not necessarily follow that those patients with CF who were disagnosed late are at a great disadvantage. Some get along well despite the delay. This may reflect the fact that the disorder takes milder form in some individuals than in others. Also each patient is unique and responds in his own distinctive manner not only to treatment but to the life situation as a whole.

FRIENDS, CAREERS AND OTHER MATTERS

"The life situation as a whole" is essentially the question with which the young adult or teenager with CF is likely to be most concerned. Physical management of the condition itself may call for a fresh approach when, for example, the older patient goes away to school. Beyond this, the problems everyone faces on growing up and becoming more independent—educational choices, establishment of mature relationships, adjustment to new environments, decisions concerning jobs and even

marriage—may make special demands on the person with a background of cystic fibrosis.

One girl, a freshman in college, has asked: "Shall I tell my friends I have cystic fibrosis?" This teenager was having her first taste of being on her own, in a setting where people knew only as much about her as she cared to reveal. She was afraid of losing the easy comradeship of her new acquaintances, and especially concerned about possible embarrassment if she needed to take treatments in their presence.

There can be no single, all-purpose answer to this or other such questions. What you feel free to tell your friends depends a great deal on the nature of the friendship. What we generally think of as a good friend is someone who is interested in us and our problems.

You may have had the experience of being asked, "Why don't you do something about your cold?" If the questioner is someone you know only casually, a full explanation on your part hardly seems necessary.

Once cystic fibrosis has been mentioned, it is important to let people know that it is not contagious. When they understand that your coughing up of mucus presents no threat to them and is beneficial to you, they will lose much of the uneasiness they have felt about it.

Suppressing your cough out of embarrassment is not in your best interest. Usually, the need to cough will diminish with more effective therapy. But certain circumstances may continue to bring on coughing spells—entering a room filled with smoke or irritating fumes, experiencing an emotional upset, or laughing.

"Shall I tell?" poses a real dilemma in connection with employment. One new college graduate, a chemistry major, obtained his first job in the laboratory of an industrial plant, only to have it threatened when the company doctor learned he had CF. A waiver of his employee insurance enabled him to continue. When questions concerning health are asked during a job interview, you might well reply that you have a "mild" or "well-controlled" case of cystic fibrosis. The fact that you are out in the labor market competing with others, asking no special consideration, should be evidence that your statement is a realistic one.

You may offer to provide information about the nature of your condition and about CF in general. Lack of knowledge often is associated with lack of understanding and with fear. Your physician usually will be glad to write to or talk with your proposed employer about you and CF.

It is generally a good idea, incidentally, if you have been covered by Blue Cross under a family plan to convert to a personal policy before your nineteenth birthday. A new application after this time might not be accepted.

Most young people have their share of awkward moments when they start dating, and those with cystic fibrosis sometimes have more than their share. Celia, who recently got married, recalls one of her first dates, which she considers a turning point. "As a child I felt socially unacceptable," she says. "When anyone asked me about my cough or breathing difficulties, I avoided telling the truth and said I had 'a frog in my throat' or had 'swallowed the wrong way.' Then, in high school a boy asked me out. I had a particularly bad night, coughing and barely able to talk. When he took me home, I fled from the car in complete despair. But he called me up the next day and asked for another date."

From this experience Celia came to realize that people could be understanding about her condition, and that she herself could learn to look at it objectively. As she now puts it, "A difference in my body chemistry makes the mucus thick instead of thin—makes it clog the lungs and digestive tract, instead of lubricating them." Stated in these terms, the difference is not one that makes her any less a person or any less capable than others of being a good friend, companion—or wife.

When it comes to choosing a career, the young person with cystic fibrosis usually is able to follow his natural bent, although certain kinds of work may be too demanding physically for some patients.

Dan, who wanted to be a physician, has settled for becoming a biochemist. Jane has achieved her childhood ambition and is now a nurse. Betty, devoted to children, enjoys being a substitute teacher; she does not have day-to-day responsibility for any one class, and can accept assignments or not, depending on how she feels on a given morning. Bill is an acoustical engineer—exactly what he planned to be since he first started tinkering with radios and record players.

Vocational rehabilitation programs in the various states, through the Rehabilitation Services Administration, often can help you to attend college or provide instruction or on-the-job training for suitable types of work. Your high school or college counselor should consult with your doctor about this matter.

Nowadays young men and women with cystic fibrosis are getting married, and in some cases there have been children. Child bearing for the woman with CF may be more difficult than ususal, and there is a much higher percentage of infertility among males with CF than in the general population.

If a CF patient and a carrier were to marry, all their children, of course, would inherit at least one gene for CF and there would be a one-in-two chance with each pregnancy that the baby would have the disease.

The whole question of marriage and having children is so personal that it cannot be adequately treated in a booklet; each situation must be considered separately. This is the sort of matter you may wish to explore with your physician and perhaps with a religious adviser.

A number of other problems are best left to discussion between doctor and patient. Delay or irregularity in menstruation, which sometimes occurs in connection with CF, is an example. Some young girls worry also about slow breast development, and some boys about short stature. There are many individual differences among patients, and the doctor is usually best qualified to answer questions concerning them.

TREATMENT FOR THE YOUNG ADULT

You will find it useful to keep in close touch with the physician who is familiar with your particular case. If you are moving to another community, he or she can forward your record to another doctor and in the meantime advise you in the important matter of maintaining continuity of care. There is a tendency for patients in their late teens or twenties to drift away from doctors, Centers and regular supervision. It may be hard for an older person to have to report to a pediatrician or to a children's clinic, even while recognizing that the medical expertise and special equipment for treatment of CF may not be easily available elsewhere. Besides, it is a natural part of growing up to want to assert your independence of authority, whether parental or medical. On the other hand, it is a sign of maturity to be able to accept responsibility for your own well-being and seek the best possible care.

From any sensible point of view, it would be most unfortunate for someone who has held his own against cystic fibrosis for fifteen, eighteen, or twenty years to suffer a setback because of laxity in maintaining an adequate treatment program.

As indicated earlier, the lungs usually present the primary problem in CF. If you are one of the many whose digestive system also is involved, however, you should make a point of observing the number, consistency, odor and color of your stools. These will vary primarily with the fat content in your diet. Be able to report this information to your doctor so he can advise you regarding pancreatic enzyme supplements—both as to type and amount to be taken.

Treatment relating to lungs is directed toward thinning and moving the mucus to prevent obstruction of the smaller bronchi or airways, and preventing and controlling infection. Mucus can be coughed up more readily after being moved from the smaller into the larger airways.

Some of the treatment aids and procedures are:

1. Antibiotics: Some patients find it necessary to remain on antibiotics most of the time, while others require them only to control infections. It is very important that your antibiotic therapy, which may be either by mouth or aerosol, should be directed by your physician.
2. Bronchial (postural) drainage. (Instructions for performing drainage follow this list.)
3. Aerosols: Various medications are inhaled and deposited directly in the tracheobronchial tree:

   These include:

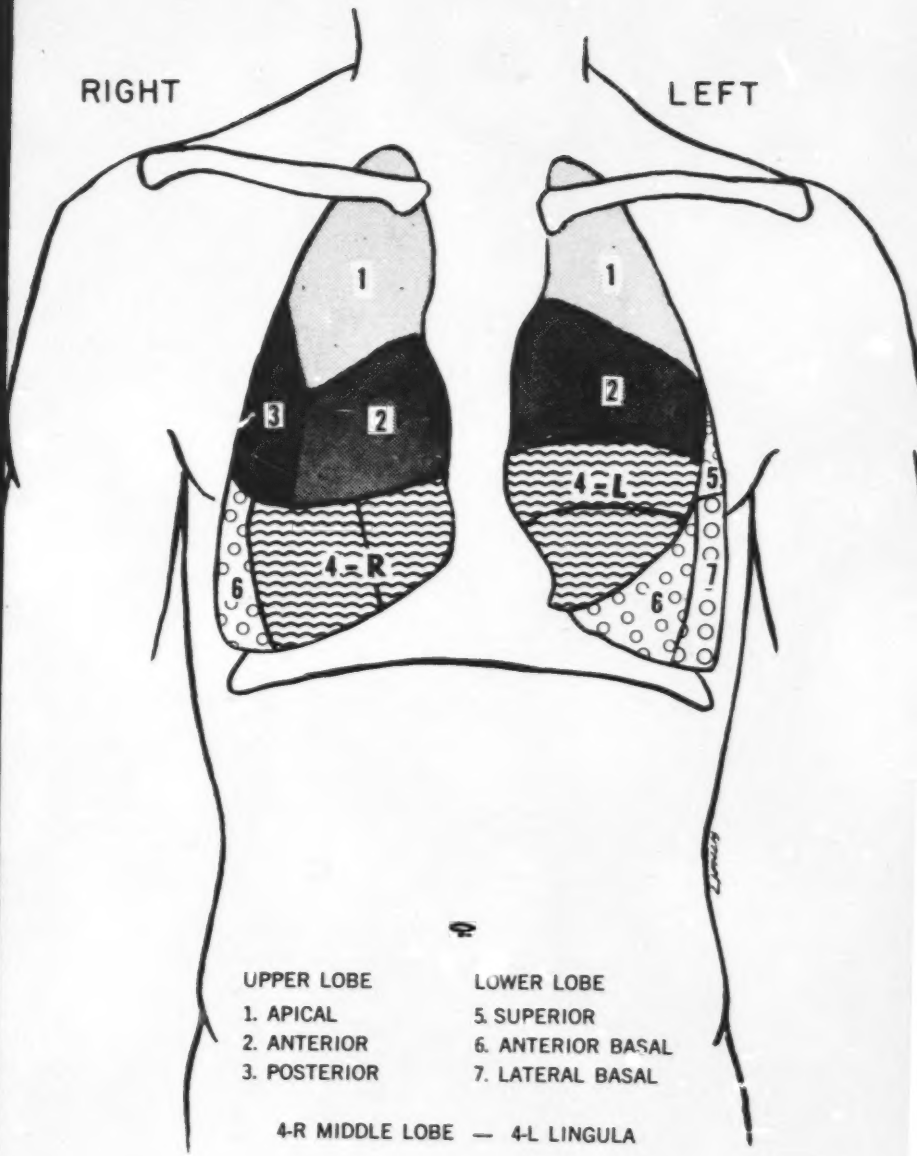
   a. Water or salt particles (normal saline).
   b. Decongestants to shrink swollen mucous membrane lining of tracheobronchial tree.
   c. Bronchodilators to widen the breathing tubes by relieving spasms of the muscles in the walls of the bronchi.
   d. Mucolytic agents to liquefy secretions.
   e. Antibiotics (see 1).
4. Mist tent: Mist of small particles of water may be recommended to thin mucus. Salt solution or propylene glycol (5-10%) may be added to the water mist to increase its effectiveness.
5. Oral expectorants: These are also recommended by some physicians to thin the mucus.

Bronchial, or segmental, postural drainage is a type of physical therapy that helps move mucus from smaller airways into larger airways, to be coughed up. This may be thought of as a process similar to tapping a catsup bottle on the bottom of the bottle.

In order to perform such drainage effectively, it is necessary to understand the basic principles of structure and function of the lungs. As a child you may have been placed in one position or another during chest physical therapy, without knowing why it was necessary. Once you have a clear idea of the division of the lung into its various parts, you can see why proper positioning is essential to obtain good results. (See illustrations, pp. 9, 10 and 11.)

The first step in adequate bronchial drainage is positioning so that the segment you wish to drain is uppermost, with the bronchus from that segment directed from ceiling to floor, or as nearly so as possible. In this way gravity will help the mucus to flow down into the larger bronchi.

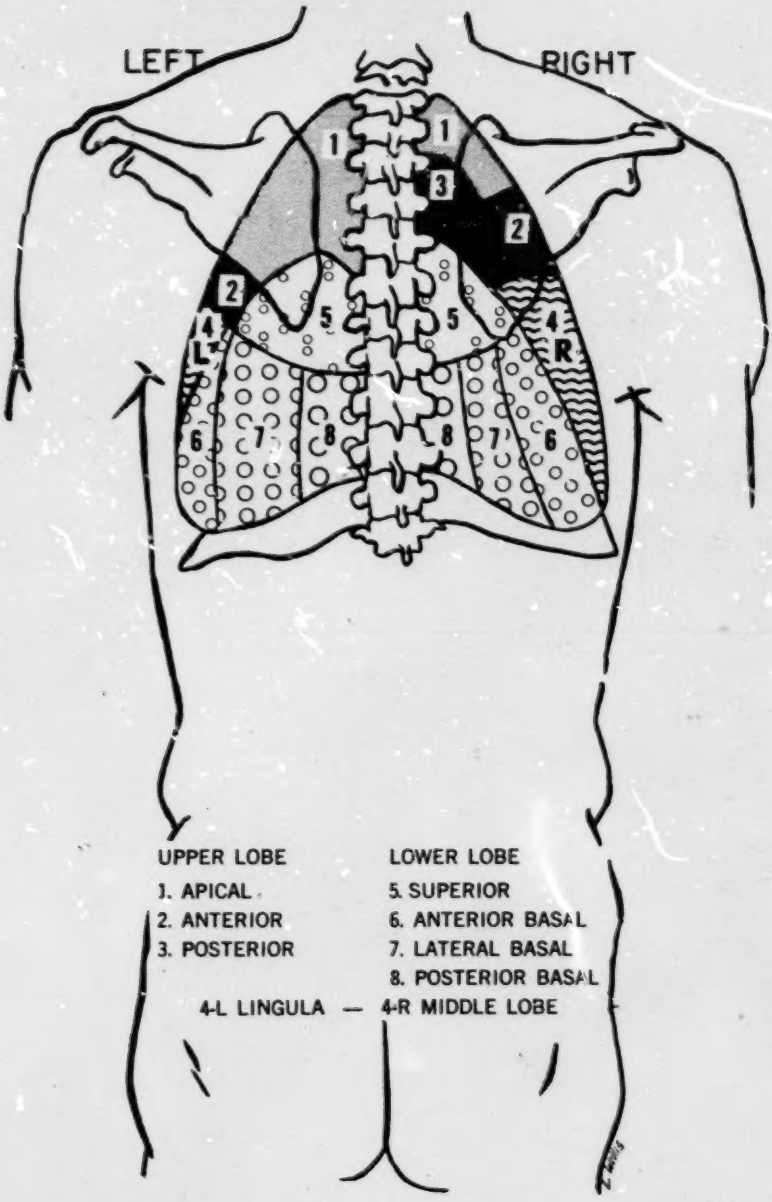
You should consult your physician about which segments should be drained in your case and ask him to give specific instructions for each segment.

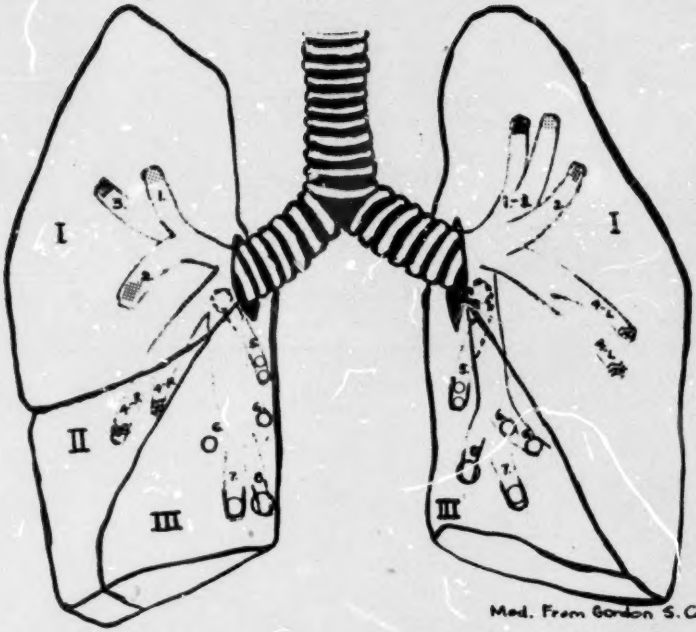


UPPER LOBE
1. APICAL
2. ANTERIOR
3. POSTERIOR

LOWER LOBE
5. SUPERIOR
6. ANTERIOR BASAL
7. LATERAL BASAL

4-R MIDDLE LOBE — 4-L LINGULA


LEFT
RIGHT
1
1
3
2
2
4
L
5
5
4
R
6
7
8
8
7
6
UPPER LOBE
1. APICAL
2. ANTERIOR
3. POSTERIOR
LOWER LOBE
5. SUPERIOR
6. ANTERIOR BASAL
7. LATERAL BASAL
8. POSTERIOR BASAL
4-L LINGULA — 4-R MIDDLE LOBE



I UPPER LOBE
1. APICAL
2. ANTERIOR
3. POSTERIOR
4-L LINGULA

III LOWER LOBE
5. SUPERIOR
6. ANTERIOR BASAL
7. LATERAL BASAL
8. POSTERIOR BASAL

II ≅ 4-R RT. MIDDLE LOBE

After positioning, the next step in bronchial drainage is to loosen the sticky mucus from the walls of the bronchi so that plugs of mucus can be moved by gravity or coughing. This is done either by clapping over that portion of the chest that is being drained or by vibrating. Clapping is done with the hand cupped to cushion the impact, making it possible to deliver a stronger impulse with less discomfort. Vibration can be accomplished by tensing the muscles of the arm and vibrating from the shoulder. Extremely important is the use of a deep breath and a strong cough, at the end of each position, to help remove mucus that has been loosened.

MECHANICAL AIDS

Mechanical aids, such as electric percussors, have been developed. There is a need for equipment the patient himself can use when no one is available to perform therapy in the conventional manner. However, you can do the regular manual clapping and vibrating in certain positions yourself, and your doctor will advise you as to the possible advantage or drawbacks in your specific case of using one of the aids.

Two of the several positions in which the individual can perform self-therapy are illustrated.

Upper Lobe, Posterior Segment

Lean forward over back of chair on folded pillow at about 30° angle. Clap with cupped hand and vibrate over upper back extending fingers forward and upward.

Right Middle Lobe

Foot of bed elevated 10-14 inches, about 15° angle. Lie on left side ¼ turn, head down (pillow behind from shoulder to hip), knees flexed. Clap and vibrate over right nipple.

Bronchial drainage may be recommended one or more times a day, often in the morning after awakening and before bedtime. Treatment soon after meals should be avoided since this is likely to cause discomfort or vomiting.

The effectiveness of drainage may be enhanced by a preceding aerosol to thin the mucus, widen the bronchi or shrink the lining of the bronchi.

If you are a student living away from home, you may be able to obtain help with bronchial drainage from a roommate, nurse or therapist at the college infirmary or local hospital. Medical students often welcome the opportunity to perform this kind of service. Some women who are employed as nurses also rent out rooms. It might be possible for you, whether as a student or as a young businessman or woman, to find such a landlady who would be willing to work with you on drainage.

If you are married, your husband or wife can assist you.

Insofar as is feasible, schools and colleges will cooperate in helping students to find living quarters where necessary equipment can be accommodated.

EXERCISE

When you were younger, you may have been taught breathing exercises; but now, with the older person's ability to comprehend the theory behind the practice, you are perhaps ready for a brief refresher course. Do you avoid taking deep breaths? Do you use accessory muscles of respiration instead of the main muscles? This is likely to result in an inadequate supply of air reaching the lungs and may lead to poor posture, rounded shoulders and a barrel chest. Special breathing exercises can effect an improvement.

In the basic exercise, the patient sits half upright, with his back supported, and relaxes his chest muscles. One hand on his chest and the other over his upper abdomen, he breathes in slowly through the nose, with minimum motion of the rib cage, his upper abdomen swelling beneath his hands as the diaphragm descends. Expiration (breathing out) should be timed to a slow count of three.

Stair climbing or walking up hill provides good exercise, again with expiration timed to the same deliberate count.

Leg raising, sit-ups, push-ups, side bends, forward bends and weight lifting contribute to strengthening the abdominal and shoulder muscles and to keeping the chest flexible. Physical activity in general helps to prevent the accumulation of secretions in the lungs and is desirable to the extent of each individual's tolerance. Tennis, dancing, golfing, skiing and horseback riding are usually recommended; swimming is encouraged by most doctors, although some urge the use of nose clips and not all

approve of diving. Skipping rope may supplement bronchial drainage to loosen mucus in the upper lobes.

NOW THAT YOU ARE RESPONSIBLE

When you have assumed responsibility for your own treatment, be sure not to neglect taking such medications as may be needed, including diet supplements. If there is a chapter of the Cystic Fibrosis Foundation in your area, it may have a drug plan to save you money on these items. In communities without chapters, the social service departments of the hospitals may be able to direct you to sources of assistance to which you are entitled. Under the state vocational rehabilitation programs mentioned earlier, necessary equipment may sometimes be provided without charge and drugs may also be made available until such time as the trainee becomes employed. State Crippled Children's Services also may provide medications.

DIET—PANCREATIC SUPPLEMENTS

By now you have a good idea of what foods you can digest easily, and what kinds should be eaten more sparingly. Butter, peanut butter, cream, vegetable oil, french fries, fatty meat, shortening, rich pastry and fried foods are likely to belong to the latter category. If you are invited to a cookout where hot dogs, hamburgers, potato chips and cake are on the menu, you will probably be safe in forgetting the rules for a change and increasing pancreatic enzyme supplements. But on a day-to-day basis eat planned, balanced meals; avoid the soft-drink-and-snack diet, high in carbohydrates and low in protein, that is popular among the younger set. And in warm weather or when you are perspiring more than usual, remember to take extra salt as protection against salt depletion and heat stroke.

SMOKING

A word is in order about smoking. A Committee on Diseases of the Chest reporting to the American Academy of Pediatrics had this to say: "Smoking of tobacco in cigarettes is clearly related to the induction of lung cancer and brings about other serious cytologic and emphysematous changes in the respiratory tract and induces detrimental changes in the cardiovascular system. Deleterious effects from cigarette smoking are directly related to both the intensity and the duration of smoking. A majority of individuals acquire the habit of smoking during childhood or adolescence; therefore, individuals acquiring the habit at this time in life undertake the greatest risk to health." People with cystic fibrosis *must* avoid not only cigarette smoking but tobacco in any form.

WHERE TO LIVE

Given free choice of where to go to school or where to live, the cystic fibrosis patient may derive some benefit from a mild, even climate. It is hard to prove, however, that climate is a significant factor in the patient's well-being; thus physicians often caution parents against moving their families from familiar surroundings and an assured livelihood to some other part of the country where a fresh start must be made. On the other hand, doctors consider it vitally important for the patient with CF to have adequate treatment facilities. If possible, you should try to live within comfortable driving distance of an active Cystic Fibrosis Center or clinic in order to benefit from the up-to-date knowledge and equipment available in such locations.

CHECKUPS

Make a point of getting acquainted with a Center, a clinic or a physician specializing in CF. When you are feeling fit is a good time to get to know your doctor, and to let him get to know you. It would also be desirable to agree on a schedule for regular checkups. Preventive inoculations including influenza vaccine may be recommended by the doctor.

One important reason for keeping in touch with a doctor or CF care facility is that there may be new developments in treatment from time to time, and you should be in a position to benefit by them. Early detection of progressive lung involvement is important so that more aggressive treatment can be started. If some complication such as diabetes should develop, early recognition by the physician may save a period of hospitalization or disability. Diabetes, incidentally, can be easily controlled today.

YOUNG ADULT COMMITTEE

To help the growing number of young adults with CF achieve their full potential and take their rightful place in society, the Cystic Fibrosis Foundation has formed a Young Adult Committee. The membership consists of doctors, including CF Center directors, a young adult with CF, and representatives of business, education, church groups and the social work profession. Liaison is maintained with the federal government where there is interest on the part of the Rehabilitation Services Administration in developing greater employment opportunities for CF patients. It was through the collaboration of the Young Adult Committee and the Social and Rehabilitation Service of the Department of Health, Education and Welfare that the study of problems confronting young adults with cystic fibrosis (see Foreword) was carried out.

The results of the work of this committee, implemented on the local level, should be increasingly felt by you and others in your situation as time goes on.

THE LONG VIEW

So far, this booklet has concentrated pretty much on the kinds of problems you are already encountering or will be called on to deal with in the near future. It is natural for you to want to look further ahead and to wonder what the long-term prospects are. A lot has been said and written about finding a control. How good, actually, are the chances for this? And if one is found, what will it mean to the individual patient–YOU?

Because cystic fibrosis is a disease of unusual complexity, prediction about it is more than ordinarily difficult. We are faced with a puzzle, or series of puzzles. What is the common link between the abnormal glandular activity and the increased salt in the sweat? The high salt content of CF sweat appears to be related to some irregularity in the process by which salt and water are transported in the sweat gland. This in turn seems to be linked to another abnormality–that of a chemical substance involved in the transport of materials through the cell wall. What is the nature of that abnormality?

Recently, over a comparatively short period, a number of promising leads and clues have emerged. Scientists are working like cryptographers to crack the code of CF. Even before the code yields its secrets, however, there is no reason why methods of treatment cannot be improved. That this is already taking place is indicated by the survival of more and more children with CF to adulthood.

The control itself, if found, might well prevent thick mucus from forming or from retaining its viscosity, once formed. Then breathing would become easier and infections could be kept to a minimum. Damage to lungs and other organs might be avoided entirely.

There is cause, then, to face the future with greater optimism than would have seemed justified even a few short years ago. Recognizing this, research workers are applying to the Cystic Fibrosis Foundation for grants in greater numbers than ever before. They believe they are on the trail of something significant and are asking to be supported in their efforts to track it down. The Foundation is doing everything it can to provide such support and also to assist investigators in the field of CF to obtain increased grant funds from the federal government.

The Cystic Fibrosis Foundation, either through local chapters or national headquarters, stands ready to serve you at any time. The National Office address is 3379 Peachtree Road, N.E., Atlanta, Georgia 30326.

The list of Centers established and maintained with the help of CFF follows:

CYSTIC FIBROSIS FOUNDATION CENTERS

Children's Hospital
Birmingham, Alabama

University of South Alabama
Mobile, Alabama

Good Samaritan Hospital
Phoenix, Arizona

Tucson Medical Center
Tucson, Arizona

University of Arkansas Medical Center
Little Rock, Arkansas

University of California
Davis, California

Cedars-Sinai Medical Center
Los Angeles, California

Children's Hospital
Los Angeles, California

UCLA School of Medicine
Los Angeles, California

Children's Hospital of Northern California
Oakland, California

Children's Hospital of Orange County
Orange, California

Children's Hospital at Stanford
Palo Alto, California

San Bernardino County General Hospital
San Bernardino, California

University Hospital
San Diego, California

Children's Hospital of San Francisco
San Francisco, California

University of California Medical Center
San Francisco, California

University of Colorado Medical Center
Denver, Colorado

Saint Francis Hospital
Hartford, Connecticut

Yale University School of Medicine
New Haven, Connecticut

Wilmington Medical Center
Wilmington, Delaware

Children's Hospital of the District of Columbia
Washington, D.C.

Broward General Medical Center
Ft. Lauderdale, Florida

Shands Teaching Hospital
Gainesville, Florida

Baptist Memorial Hospital
Jacksonville, Florida

University of Miami School of Medicine
Miami, Florida

Florida Hospital CF Center
Orlando, Florida

Bureau of Crippled Children Respiratory Clinic
Pensacola, Florida

All Children's Hospital
St. Petersburg, Florida

University of South Florida
Tampa, Florida

Emory University School of Medicine
Atlanta, Georgia

The Respiratory Center
Medical College of Georgia
Augusta, Georgia

Kauikeolani Children's Hospital
Honolulu, Hawaii

Mercy Medical Center
Nampa, Idaho

Children's Memorial Hospital
Chicago, Illinois

Northwestern University Young
Adult Chest Clinic
Chicago, Illinois

University of Chicago School of Medicine
Chicago, Illinois

Loyola University
Stritch School of Medicine
Maywood, Illinois

St. Francis Hospital
Peoria, Illinois

Elkhart General Hospital
Elkhart, Indiana

Deaconess Hospital
Evansville, Indiana

Methodist Hospital
Indianapolis, Indiana

Riley Hospital
Indianapolis, Indiana

University of Iowa Hospital
Iowa City, Iowa

University of Kansas Medical Center
Kansas City, Kansas

St. Joseph Hospital
Wichita, Kansas

University of Kentucky Medical Center
Lexington, Kentucky

Norton's Children's Hospital
Louisville, Kentucky

Tulane University School of Medicine
New Orleans, Louisiana

Louisiana State University School of Medicine
Shreveport, Louisiana

St. Joseph Hospital
Bangor, Maine

Central Maine General Hospital
Lewiston, Maine

Maine Medical Center
Portland, Maine

Johns Hopkins Hospital
Baltimore, Maryland

National Institutes of Health–NIAMDD
Bethesda, Maryland

Children's Hospital Medical Center
Boston, Massachusetts

Massachusetts General Hospital
Boston, Massachusetts

Bayside Medical Center
Springfield, Massachusetts

University of Michigan
Ann Arbor, Michigan

Children's Hospital of Michigan
Detroit, Michigan

Mott Children's Health Center
Flint, Michigan

Butterworth Hospital
Grand Rapids, Michigan

Ingham Medical Center
Lansing, Michigan

University of Minnesota
Minneapolis, Minnesota

Mayo Foundation
Rochester, Minnesota

University of Mississippi
Jackson, Mississippi

University of Missouri Medical School
Columbia, Missouri

Children's Mercy Hospital
Kansas City, Missouri

Cardinal Glennon Memorial Hospital
for Children
St. Louis, Missouri

St. Louis Children's Hospital
St. Louis, Missouri

University of Nebraska Hospital
Omaha, Nebraska

Elliot Hospital
Manchester, New Hampshire

Hackensack Hospital
Hackensack, New Jersey

Monmouth Medical Center
Long Branch, New Jersey

Morristown Memorial Hospital
Morristown, New Jersey

University of New Mexico School of Medicine
Albuquerque, New Mexico

Albany Medical Center
Albany, New York

Long Island College Hospital
Brooklyn, New York

Children's Hospital of Buffalo
Buffalo, New York

Charles S. Wilson Memorial Hospital
Johnson City, New York

Long Island Jewish Medical Center
New Hyde Park, New York

Babies Hospital
Columbia-Presbyterian Medical Center
New York, New York

Mt. Sinai School of Medicine
New York, New York

University of Rochester
Strong Memorial Hospital
Rochester, New York

St. Vincent's Medical Center of Richmond
Staten Island, New York

Robert C. Schwartz Clinic
Upstate Medical Center
Syracuse, New York

Westchester County Medical Center
Valhalla, New York

The House of the Good Samaritan
Watertown, New York

Good Samaritan Hospital
West Islip, New York

University of North Carolina Memorial Hospital
Chapel Hill, North Carolina

Duke University Medical Center
Durham, North Carolina

Akron Children's Hospital
Akron, Ohio

Children's Hospital of Cincinnati
Cincinnati, Ohio

University Hospitals of Cleveland
Cleveland, Ohio

Children's Hospital
Columbus, Ohio

Children's Medical Center
Dayton, Ohio

The Toledo Hospital
Toledo, Ohio

Children's Memorial Hospital
Oklahoma City, Oklahoma

Hillcrest Medical Center
Tulsa, Oklahoma

University of Oregon Medical School
Portland, Oregon

Harrisburg Polyclinic Hospital
Harrisburg, Pennsylvania

Children's Hospital of Philadelphia
Philadelphia, Pennsylvania

Hahnemann Medical College and Hospital
Philadelphia, Pennsylvania

St. Christopher's Hospital for Children
Philadelphia, Pennsylvania

Children's Hospital of Pittsburgh
Pittsburgh, Pennsylvania

Mercy Hospital
Wilkes-Barre, Pennsylvania

University of Puerto Rico Medical School
Rio Piedras, Puerto Rico

Rhode Island Hospital
Providence, Rhode Island

Medical University of South Carolina
Charleston, South Carolina

Greenville General Hospital
Greenville, South Carolina

McKennan Hospital and University of
South Dakota School of Medicine
Sioux Falls, South Dakota

Le Bonheur Children's Hospital
Memphis, Tennessee

Vanderbilt University Medical Center
Nashville, Tennessee

Children's Medical Center
Dallas, Texas

Baylor College of Medicine
Houston, Texas

Santa Rosa Medical Center
San Antonio, Texas

University of Utah Medical Center
Salt Lake City, Utah

Medical Center Hospital of Vermont
Burlington, Vermont

University of Virginia
Charlottesville, Virginia

Eastern University Medical School
Norfolk, Virginia

Medical College of Virginia
Richmond, Virginia

Children's Orthopedic Hospital
and Medical Center
Seattle, Washington

Deaconess Hospital
Spokane, Washington

West Virginia University Medical Center
Morgantown, West Virginia

University of Wisconsin Medical Center
Madison, Wisconsin

Milwaukee Children's Hospital
Milwaukee, Wisconsin